DOCUMENT RESUME

ED 276 221 EC 190 987

AUTHOR Ferguson, Dianne L.
TITLE Mothering a Handicapped Child: Roles for Mothers of Young Adults with Severe Disabilities.
PUB DATE Apr 86
NOTE 29p.; Paper presented at the Annual Meeting of the American Educational Research Association (67th, San Francisco, CA, April 16-20, 1986).
PUB TYPE Speeches/Conference Papers (150) -- Reports - Descriptive (141)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS Adolescents; Education Work Relationship; History; Interviews; *Mother Attitudes; Mothers; *Organizations (Groups); Parent Role; Public Policy; Qualitative Research; *Severe Disabilities; *Social Support Groups; Young Adults

ABSTRACT

The study examined the experiences of seven mothers of severely handicapped young adults and adolescents by means of focused interviews. A review of the literature examined qualitative research with the handicapped and the rise of parent organizations which fought for public education rights. The roles and activities of the seven mothers in such organizations when their children were young are noted. New policy initiatives targeted toward supported work and small community-based residences for severely disabled adults are viewed by the mothers with caution. The discrepancy between public policy and the present reality of very limited services has made some mothers realize they must develop new strategies to negotiate with an adult service system that has no legal mandate to provide services. The influence of the historical time period on family and group development and lack of utilization of non-professional, informal support networks by these mothers are also discussed. A six-page list of references is appended. (DB)

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Mothering a Handicapped Child: Roles for Mothers of Young Adults with Severe Disabilities

Dianne L. Ferguson

University of Oregon

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Presented as part of a symposium entitled, ASPECTS OF INVOLVEMENT: WOMEN AS MOTHERS, STUDENTS, TEACHERS, AND GRADUATES IN SPECIAL EDUCATION. AERA Annual Meeting, April 16-20, 1986, San Francisco.

EC190987

Mothering a Handicapped Child: Roles for
Mothers of Young Adults with Severe Disabilities

Mothers (and fathers) of handicapped children are not pre-selected on the basis of their qualifications and knowledge. Yet a child's disability can multiply the difficulties of childrearing. If the child's disabilities are severe, then the challenge grows even more daunting. Predictably, it's mainly mothers who must face the daily versions of this challenge. Even though some modern fathers increasing help with some aspects of "family work," especially when both parents work (Pleck, 1985), the bulk of the care for society's chronically ill, elderly, and handicapped members remains clearly women's work (Finch & Groves, 1983).

Since colonial times, handicapped children and youth have usually captured society's attention only when the inadequacy of family resources forced the community to assist. As long as the family could support its members, whether ill, old, disabled, or alone, the community did not breech their privacy. Even in the nineteenth century when the state began to intrude more directly into family life, the intrusion was more often motivated by the family's condition of poverty than by a child's disability alone. Still today, it is the economic issues surrounding educational, residential, medical, and vocational programs for handicapped children and youth that most often determine the services provided (Ferguson & Ferguson, in press). The primary location of basic, daily care and support for dependent members of society largely remains part of the female domestic sphere, separated and isolated from the public world of work, school, society, and production (Shapiro, 1983).

Although there is no dearth of professional research and literature about mothers of handicapped children, most focuses exclusively on mothers of infants

and young children (e.g., Blacher, 1984; Bromwich, 1981; Glendinning, 1983). Even mothers who provide their own accounts limit their narratives to their childrens' early years (e.g., Featherstone, 1980; Park 1967; Pieper, 1977; Schaefer, 1978). Now among both professional and parent writers there is an emerging interest in the entire life span of families with disabled members (Park, 1982; Schaefer, 1982; Turnbull & Summers, 1985). Nevertheless, little attention yet falls past early childhood or school years to consider the experiences of parents when their children become adults.

This paper examines the experiences of mothers whose moderately and severely handicapped children are now young adults. First, the paper introduces the unique roles mothers of severely handicapped children must fill. Second, it explores these roles through the experiences of this particular generation of mothers. Finally, it reports the new role crises these mothers face as their sons and daughters move into adulthood.

Methods and Participants

The data for this paper come from a larger study of families whose severely handicapped youth are in transition from school to adulthood. This larger study seeks to examine how such families cope with the distressingly frequent situation of no adult services at all when schooling ends.

The seven mothers in this report all have sons or daughters labeled severely handicapped who range in age from 12 to late 20s. One mother has three such children, while the remaining six have one each. Of the nine young adults, three have completed their schooling, three are graduating this year, and three have one or more years remaining.

Though all are labeled severely handicapped, these youth possess a wide range of abilities. According to the United States Office of Special Education

and Rehabilitation Services, severely handicapped individuals are those with severe delays (three or more standard deviations) in two or more areas of development. Thus, the traditional categories of moderate, severe and profound retardation, multiple physical and sensory handicaps, and autism are included. Severely handicapped persons are also defined by their primary need for functional skills, rather than traditional academic content, in educational programs.

The seven women range in age from late 30s to 50s. Only one has a consistent full-time work history, occasioned in large part by a divorce and period of single parenthood. One other mother has consistently assisted at least part time in a family business. Four mothers have not worked, though one recently began working for an advocacy organization involved in training parents of handicapped children and young adults. Finally, one mother has worked in the past for pay, but is now actively involved only in volunteer work. I met two of the mothers through a parents advocacy organization which focuses on the period of transition for severely handicapped young adults. These mothers referred me to others. Of the mothers called and invited to participate, only one has declined.

All data are being gathered through focused interviews (Taylor & Bogdan, 1984; Maccoby & Maccoby, 1954) in the tradition of qualitative research. Although qualitative research is still somewhat unusual in special education, as a research perspective it has a rich intellectual history and methodological complexity (Taylor & Bogdan, 1984; Lincoln & Guba, 1985). The academic origins of the qualitative perspective (also referred to as "ethnographic," "naturalistic," or "interpretive" research) are in the fields of sociology (Denzin, 1978) and anthropology (Geertz, 1979). However, there is an

increasing recognition of the value of the method to education in general (Bogdan & Biklen, 1982; Reynolds, 1980/81; Rist 1977; Rist, 1984), and to special education in particular (Heshusius, 1982; Kielhofner, 1979; Stainback & Stainback, 1984a; Stainback & Stainback, 1984b).

Within the field of mental retardation there is a small but growing tradition of qualitative research beginning with Edgerton's classic study (1967) and developing into the areas of residential services (Bercovici, 1983), vocational training (Kielhofner, 1983), the family life of children (Goode, 1984), and parent advocacy movements (Jacobs, 1969). Furthermore, qualitative research has a respected history and particular utility in the investigation of such notoriously slippery and private areas as natural family life and social culture (Charmaz, 1980; Fine & Kleinman, 1979; Geertz, 1983; LaRossa & Wolf, 1985; Stack, 1974). Thus it seems the appropriate methodological vehicle for gaining an in depth understanding of the experiences of parents during the critical period of transition.

Taped interviews lasted from one to two hours and two of the mothers have already participated in second interviews. Initial analysis of these early interviews revealed several emerging themes and issues surrounding mothers' on-going roles with their adult severely handicapped children. The remainder of this paper will discuss these preliminary research findings together with the larger historical and social context within which these findings must be understood.

The Context of Care

Special education emerged at the turn of the century largely as a result of compulsory education (Anderson, 1917; Mitchell, 1916; Phillips, 1934/35). Although some moderately and severely retarded students found their way into

these early ungraded classes, they were soon excluded with the help of the new and powerful IQ test. Some large cities later established "low-ability" or "low IQ" classes (Smith, 1940/41; Wallin, 1966), but most students scoring less than 50 on IQ tests were excluded as "unteachable" (Berry, 1931; Hungerford, 1964; Wallin, 1966).

After World War II parents of excluded children began to organize. Coalitions of many small parent groups and councils resulted, in 1951, in the National Association of Parents and Friends of Mentally Retarded Children (Segal, 1970), now the National Association of Retarded Citizens. Through such organizations parents began to create the programs society denied them, running them in homes, church basements, and civic buildings, and funding them with private fees, donations, and what state and local funding was available.

Although many fathers were involved in the movement from the beginning, the mothers really fueled this grassroots activism (Bair, 1981). However, they saw their volunteer activism not as a culturally permitted alternative to paid work, but as a necessary extension of their mothering. First they turned to other women in their family networks for support. Gradually they met other mothers of retarded children and became the squeaky wheels demanding the grease of public programs.

Familiar child-rearing responsibilities get expanded for mothers of handicapped children. They must assume not only nurture and care of their handicapped children, but they must also secure and maintain a wide variety of necessary medical, educational, social and community services. While some (Helterline, 1980) describe all modern motherhood as equally broad -- as requiring constant care for all facets of the child's life -- the scope of motherwork and care for mothers of handicapped children, especially severely

handicapped children, is different in several ways.

First, the labor of constant, daily, care can be very wearing, particularly if the child has significant physical disabilities. The "daily grind" of tending to basic physical needs can acquire the Sisyphean character of housework rather than the "productive" quality of child care (Baldwin & Glendinning, 1983). After all, the job of rearing a child implicitly promises a goal of eventual "unemployment" -- "a successful mother brings up her children to do without her" (cited in Baldwin & Glendinning, 1983, p. 55). But for mothers of severely handicapped children, daily routine, prolonged dependency, and slow changes in children's skills can mean that mothers' roles change very little over time. When other mothers struggle to adjust to an "empty nest," mothers of severely handicapped children face coping with a nest that may never be empty. "Motherhood" risks becoming oppressively permanent, not merely in status, but in the unchanging duties that would otherwise fade away.

In addition to a difference in the quality of care work required, there is a difference in the type of care work required. Like women who care for family members who are sick or elderly, mothers of severely disabled children frequently spend a lot of time in hospital, clinic, and other medical settings. Repeated surgeries, expensive equipment which must be periodically serviced and replaced, administration of medications, therapies, and other basic health maintenance services can swallow up all of a mother's time and energy.

Finally, although it is culturally normative for all mothers to interact with schools on behalf of their children (Arnot, 1984; Lightfoot, 1977), mothers of handicapped children have had unique relationship.

Early Advocacy

The mothers I talked with bore their children in the late 50s and early 60s when grass roots activism targeting the schools began to result in publically sponsored educational services. Throughout their children's lives this generation of mothers has been at the forefront of change in special education. Their children were the first to attend special early intervention programs, and first to attend publically sponsored, though segregated, school programs. Later, their children were the first to move to federally mandated, integrated public special education programs.

In various ways the mothers I talked with joined these on-going battles on behalf of their children. Gwen Simpson (1) began reading -- pamphlets, books, articles. She soon discovered the Margaret Harris Center, but found that they had no programs for young children. On her own Gwen visited and observed the classes, copied the materials she saw and began teaching her daughter at home. At three her daughter was "the youngest person ever to attend" the Center, despite the fact that she was not yet toilet-trained, a program prerequisite. Gwen drove her young daughter and a new baby 24 miles every morning for a three hour program. Soon she started finding things to do around the school: "I took people on tours of the school. I did secretarial work. I helped out in the classroom if a teacher's aide was absent. I just filled in wherever needed."

Betty Richards' daughter, Anne, has been in programs since she was 13 months old, but only because Betty helped start a preschool program in Baleford that included both handicapped and non-handicapped children. Later, Anne also began attending the Center program, though she remained in the regular preschool program as well until she was seven.

Diane Mitchell, Harriet Sears, Sharon Davis, and Janet Swinburne, all

found that for their young handicapped children, the Center was "the only place in town." When there are so few alternatives, it is hard to be critical. Still, at least one mother voiced a strong reaction:

> ...what I didn't like about <it> is that you feel like a charity case. I mean, they'll "take you in and help your little boy." I didn't like feeling like that. It kind of makes you feel obligated to them like she <Margaret Harris> was this big goodwill person. I mean, I think it should be a publically funded school system...

By this time there was a clear trend to provide public school educational services, thanks largely to parent activism. Between 1951 and 1953, 25 states, either through law or policy, officially provided public services to "trainably" retarded students (as they were called then) at least permissively (Goldberg, 1958; Hungerford, 1964). But parents found a decade later that there were few choices. What there were rarely included a place in public school settings.

Other changes occurred during this period as well. The period up to 1975 saw expansive growth in the number of classes for all kinds of special students. "Emotionally disturbed," "learning disabled," "perceptually handicapped," hyperactive," and other new labels, began to dominate special classes (Sarason & Doris, 1979). During the 1960s a few special educators began questioning the efficacy of segregated special classes for mildly handicapped students (Reynolds, 1962; Dunn, 1968; Lilly, 1970). At the same time, many special classes became disproportionately populated by poor, non-white, and sometimes, non-English speaking students (e.g., Mercer, 1973). These developments, together with an increasing educational awareness of the concept of normalization (Wolfensberger, 1972) led to a new effort to

"de-label" and mainstream many mildly handicapped students. Mainstreaming fueled other efforts to produce federal legislation guaranteeing education to all students, regardless of type or degree of handicap.

Though still prior to P.L. 94-142, all of the children in this group moved from segregated to public school integrated classrooms. For Alison Richards "mainstreaming" began when she was seven. "And she was really thrilled with that. She loves being in the public school. She just started making all kinds of progress." John Davis, Mary Simpson and Mark Tillman were all members of the "first two public school programs in Pine County for TMR students."

Gloria Swinburne had spent one year with a special education teacher in an elementary school in a district near her home, but was transferred because the classroom was for "high level kids." Her new placement at an Easter Seal Treatment Center was also short-lived because "she didn't fit into that category at all....it was her mental <retardation> that was the bigger problem even though there were some physical handicaps." Finally, at age eight Gloria, too, arrived at the Margaret Harris Center. Later, also at age eight, Gloria was joined by her brother Bill. The very next year, Gloria's last brother, Daniel, aged five, joined his siblings at the Center where "he got off to a flying start....one of the reasons he was in one of the first classes to transfer out of Margaret Harris" to a public school. In the end, all of the Swinburne children moved to public school classrooms in Pineville.

Some mothers were very cautious, even suspicious, of the change to public school. Sharon Davis has always "been involved in the classroom." For two years she was an aide in the same school John attended. Both she and her husband felt that John's personality required her involvement -- required that she would need "to establish a good understanding with the teacher." For

Sharon, as well as Gwen Simpson and Betty Mitchell, the first years of the public school classes required a lot of time and advocacy:

> There were many deficits in the public school program when it first started. It has only developed to the extent that it has because we were in there in the beginning.... There were things lacking in the public school program originally that we had already gained at Margaret Harris and we weren't willing to let those go. So we were in there saying, "We want this thing, and that!"

Diane Mitchell found that her son also had a difficult time with the transition to public school, perhaps because he was already 14. Diane found the transition from an "intensive training" class at Margaret Harris to a regular public high school "too extreme." Although she "went along with it", she also began to

> put my foot down. I'd go down to the school district and we'd have meetings. They hated to see me coming cause I kept saying, "this isn't making any sense." But all they did was handle the education part....They wouldn't go over his whole life history and help me figure out what to do with him.

For some mothers the fight has continued in various ways, Serving on various committees and councils, driving a school bus of handicapped kids for nine years, attending meetings, testifying before the legislature, writing letters, organizing other parents, helping in classrooms have all been part of motherwork for these mothers. For most it has meant that they could not "pursue full time employment because I can't do both." Sharon Davis felt that "the timing of the situation -- the fact that John went into the first public school program " required her level of extra effort. Even though Sharon

"didn't given up some lucrative profession in order to do it," she hopes that "when he graduates...I graduate." Betty Richards is also eager for Annie to graduate. "See, personally, I've put my life on hold for the last 18 years....So I'm ready now. I want to develop myself."

Mothers and Young Adults

Now these mothers face a new "first" challenge. Latest policy initiatives and model program practices target integrated supported work and small, community-based residences as the goal for all adults with severe disabilities (Will, 1984). We now know that with proper job supports and employer incentives even severely mentally retarded people can work in businesses and factories and earn significant salaries. No more "make-work" sheltered workshops, or "no-work" day activity centers. The new direction is clearly "real work, for real pay, in real settings."

The mothers approach this future with many of the same hopes of any mother. Their children are on the threshold of adulthood and its normal attendant: independence. They would like to look forward to their children "living apart," and to new roles of increasingly distant support and involvement. Certainly the new policy initiatives and model programs support these hopes. The mothers begin to look forward to an empty nest, and to an end to full time activism, though clearly they realize their role will continue to be "different." For example, Betty Richards imagines

> ...we'll be quite involved always with Annie all her life. I guess as her mother, at this point I'm looking forward to having her live apart for awhile because I'm needing it....I see her coming home for weekends when she wants to and when that works for all of us....I see us being in touch with her foster parents...just knowing what's going

on with her and what her needs are and how we can help her.

But the present reality crushes their cautious optimism. Many graduates with severe disabilities not only do not move into a supported job upon leaving school. Many do not move into any day programming at all. Instead, they move to a waiting list. Although most of these young people eventually move off the waiting lists into day programs, or perhaps even supported jobs, how long that resolution takes varies (Brodsky, 1983). For most there will be no better paying, productive, integrated and supported jobs and living arrangements (McDonnell, Wilcox, Boles, & Bellamy, 1985; Brodsky, 1983; Zollers, Conroy, Hess, & Newman, 1984).

Instead the mothers must "fight for services" once again, or suffer the alternative: having your young adult home again, full time. For some of Gwen Simpson's friends,

> It's like you've got your infant back again. I mean, they're tied down. They can't have a job outside. They can't participate in meetings, or do anything anymore because they have this handicapped child underfoot all the time. And it's panic for them.
>
> All the mothers are nervous about this future.

Harriet Sears feels she is "racing against the clock." Although she is quite active on her daughter's behalf now, she is also able to enjoy a range of interests and volunteer activities. However,

> When Pam turns 18, I might not have as much freedom... Having a child who doesn't have vocational skills, who basically is a child who will be very, very difficult to find a good day program for -- my options are much narrower. So this would put a lot of restrictions on what I will be able <to do>.

Gradually, and often reluctantly, the mothers realize that their young adults will continue to require a lot of motherwork. As the realization matures, they confront two new problems. First, they must deal with their own reactions to this sudden loss of services and the need for on-going intensive advocacy. Second, they must develop new strategies to negotiate with an adult service system that has no legal mandates to provide services, and that is rejecting and suspicious of their on-going involvement.

Those mothers whose children are still in school look to the future with grave apprehension. Many work now to secure work and residential slots before graduation. Rose Tillman, Gwen Simpson, and Sharon Davis are members of a new parent-run advocacy network which focuses on securing successful transitions for severely handicapped young adults. Gwen feels it is a parents must help the professionals find jobs and homes for their children. Betty Richards finds the prospect of no services so frightening that she feels she must "do whatever we have to so that doesn't happen....It would be very, very difficult. It just can't be."

Rose Tillman was not as active as many mothers when her child was younger and feels that she is "taking her turn" now, paying back a debt:

> When my kid was younger, I didn't feel a sense of any kind of community or camaraderie with other women. I felt resented more than anything. I felt that the women who were working (for their handicapped kids' services) resented me because I said I was too busy. A lot of those women have burned out now, and so I think they do see that I am taking my turn and they're glad to see that happen.

Still, Rose would like to see an end to her involvement:

> It really is true, I guess, that a kid like Mike <is> going to take

> my involvement like this for the rest of my life. Feels like a lot of work. I really do want somebody else to do that at some point in time.

And Sharon Davis admits that

> I'm hanging on by my fingertips right now .... We need to be in there, but it isn't with the fervor, enthusiasm and joy that I approached preschool things or early education things. I am doing it because I have a responsibility to do it. I want his future to have some solid foundations, but I want my involvement to end also.

For parents whose young adults are already at home full time, the reactions are different. In her role as one of the team leaders of the new parent advocacy group, Rose Tillman speaks to many of these parents. She finds they are either angry or resigned. They are all fatigued and some have little hope that the system will really be able to share their responsibility.

They are angry for many reasons. First, because there are no services. The past ten years of educational entitlement lulled them into a security that the free-market style adult service system cannot offer. They are also angry at teachers for not warning them sooner. But perhaps most debilitating, they are frustratingly angry at a system that seems inadequate and inefficient at best. Jack Paterson's son is now in his forties. He has worked in four different places; but, "after a couple of weeks if he doesn't want to work, he won't, and they've no one to make him. He ends up at home." The system depends upon having a home that he can return to, but discourages parent's involvement until they are needed as a last refuge.

Bill Swinburne sits alone at home each day, "watching TV and reading books." Janet keeps calling Mental Health "every so often," but in the end,

"deep inside of me...I feel like I ought to be able to solve my own problems." Anger, combined with years of fatigue, leave mothers on their own, isolated at home with their young adults, embittered, feeling that they're "not going to get help from anybody."

What mothers are struggling for is not terribly complicated. They speak of it in various way: "a solid foundation," "a chance to work," "her own friends," "a place to live," "a chance to be happy." Perhaps most simply, "They want to see their kid in a good place." But, as Rose Tillman explains

> Most kids are not in a good place at 21. Most people haven't even done the residential hurdle yet. They haven't ever seen their kid live any place else and make it and be happy there. They want him to have a job. Something to do with himself everyday that has some dignity and worth, instead of just sitting around. I think if I could say anything that's broad, it would be that they want a life for them where this person looks secure and happy.

The situation seems bleak, the past does not serve as a template for the present. The mothers' <u>early</u> advocacy efforts were culturally supported in at least three different ways.

First, they moved easily into their activism as natural extensions of their mothering. Charged with all facets of child rearing and care, it seemed natural to develop needed services for their retarded children. Activism as appropriate motherwork was further reinforced by the fact that the organization leadership remained firmly male. As in many other social arenas, women "tended to be designated the 'doers,' while men tended to become the 'directors' (Bair, 1981, p. 154).

Second, volunteerism was a culturally appropriate way for women to work

outside the home without really leaving it (Kaminer, 1984). Of course, their volunteerism bore the tenor more of responsibility than opportunity: if a mother must produce an imperfect child, surely it is incumbent upon them to expend every effort on that child's behalf. In addition, unlike the traditional types of feminine volunteerism, the efforts of the mothers I interviewed, and their cohorts across the country, succeeded in forcing social change that went much further than simply providing free social services.

Third, it is culturally normative for women to be the primarily liaison with schools (Arnot, 1984; Lightfoot, 1977). For mothers of severely handicapped young adults, however, there are few cultural norms to follow. Their continued involvement in the lives of their adult children is counter to the more accepted outcome of child-rearing: the "empty nest." When children reach adulthood, mothers must "let go" and allow them to venture forth on their own. While this is seldom easy for any mother, it is especially challenging for mothers of severely handicapped children. As one mother put it:

> It goes against what's built into mothers naturally. The essence of parenting is to care for until this person's independent. Seeing the retarded person as independent is lots harder.

The conflict for these mothers is that even though they are tired and ready for their mothering to consume less of their energy and time, they know that their retarded children are not ready to manage alone and society has refused to provide the support for them to move from home. Instead these mothers must approach and find ways to communicate with a new group of professionals. For their part, the adult service professionals pride themselves in treating their "clients" as the adults that they truly are. Too many of the mothers find that

> Professionals always treat us like somehow or other we're being Smothermothers -- we're hanging on and it's dysfunctional. That might be true if we were talking about a normal 21 year old. But we're not. We're talking about a 21 year old kid who has extra ordinary needs and who isn't ready to go off in the world yet....<and> I don't see a lot of parents who wouldn't wish that their kid -- wouldn't trade whatever company they get from their kid for their kid being able to deal with themselves and their own lives better. They really see this person as being dependent to some degree through most of their life.

Short of formal guardianship, and perhaps even then, appropriate social roles for mothers of adult disabled children have not been fully identified. Negotiating such unexplored social pathways is further complicated by the fact that the domains of work and securing housing with which mothers must now contend are traditionally areas of unchallenged male dominance in public life. Weary but worried, these mothers of young adults with severe disabilities are struggling with how to respond, what to demand, and what to let pass.

Conclusion

It is not yet clear how these new challenges will be met. Perhaps, as in the past, mothers' advocacy efforts will force dramatic changes in the service system. Perhaps, too, they will shape new rolls for their involvement in their childrens' adult lives. Certainly there remains much to be learned about how mothers and families experience this particularly challenging transfer.

The trouble is that the normalized, cultural rite of passage, marking the end of one stage of family life and the beginning of another is unavailable to many of these. Moreover, the obstacles are much more basic than just the

limitations of the disability itself. Some mothers are forced to quit their jobs in order to stay with young adult children who have no place to go once out of school (Spolar, 1985). Other families face the logistical and financial burdens of arranging home attendant care or respite precisely at a time when offspring are supposed to be "leaving the nest" (Black, Smull, & Crites, 1984). But perhaps most stressful of all, mothers are forced to watch the slow atrophy of the functional skills and adaptive behavior that their children worked so long and hard to develop in school. All of the hard won struggles to develop integrated, functional, school programs, all of the years of meetings to work out appropriate objectives, all of the extra time spent; all of this the mothers now find threatened.

One lesson these mothers clearly teach, and should be further explored, involves the importance of the interplay between family time and historical time (Hareven, 1978). The mothers reaction to this social service/social role gap can also only be fully appreciated in light of the particular historical events that forged their entire experiences as mothers. Much more so than mothers of young severely handicapped children today, these mothers have repeatedly managed with few outside services and supports. They have learned to manage by doing it themselves, while lobbying for others to assume the responsibility. When there were no school programs, they created them. When the first school programs were inadequate, they improved them. They created new networks of mothers in similar situations, often at the expense of other existing social, family and community networks. Two decades of grass roots activism has left them well-trained, but weary, and uneager to mount a new campaign. Ironically, this history of involvement with each other may now deter them from pursuing one possible avenue for interim support.

Both the mothers and the transition planning process, as usually practiced, have tended to overlook the utility of parents' non-professional, informal support networks of family, friends, and neighbors. The potential of such networks is something that they have tended to think of just in terms of advocacy and emotional support instead of naturally occurring community resources for practical, cooperative solutions to temporary problems. Politically, such use of existing networks could provide inexpensive, flexible, and reliable short-term solutions. Further, such an informal, non-bureaucratic, non-professional solution could provide concrete assistance to families without reducing the pressure upon adult service agencies to find appropriate, stable work and living opportunities for any young person who needs them.

Yet the mothers in this report do not seem to be actively pursuing such alternatives. Some, though more reluctantly now, do turn to familiar social change networks, but not for concrete assistance. As one mother explained,

> there's something about how you learn to manage by doing it yourself, a lot, from the early years on... I think that by the time the kid gets to be 21, parents are very, very good at doing whatever they have to do by themselves. And when they run into problems, they're not as good at being cooperative... either the family, or sometimes one partner, manages. Deals with the kid. Rruns the behavior program. Deals with the kid when he's bad. Gives him the bath. Gets him dressed -- whatever there is to do. The work of it. That leads people to feeling kind of isolated and alone and, I think... doesn't contribute to learning cooperation. Perhaps things will change.

Their pasts suggest that this particular generation of women will continue to seek solutions, despite their current fatigue and frustration. Perhaps, once again, their legacy to new generations of mothers will be the services and systems that genuinely support severely handicapped young adults.

Author's Notes

(1) All names of persons and places have been changed to ensure anonymity.

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